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Chapter 18

The Registration Network of Family Practices and cognitive aging research

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ABSTRACT

This study describes the involvement of the Department of General Practice of the University of Limburg in MAAS. Several epidemiological studies concerning pathological cognitive aging have been performed with the continuous morbidity database of the Registration Network of Family Practices (RNH). This register serves as the sample frame for the MAAS panel studies. Several projects have been initiated on the basis of the combined data on health and background characteristics in this register and the MAAS data base. These projects are described in short below.

INTRODUCTION

The Department of General Practice participates in MAAS in several ways. It organizes the Registration Network of Family Practices (RNH), which serves as the sample frame for subject selection in the MAAS studies (see Section 4.4). The register contains demographic background information and continuously recorded morbidity data on the patients of 42 general practitioners in 15 practices, via a computerized record system. Several ongoing projects are based on a combination of the MAAS/RNH data sets and are discussed briefly in the final section. A combination of both MAAS and RNH data will eventually enable incidence studies to be carried out into age-related cognitive disorders and psychopathology of subjects investigated in MAAS. Furthermore, research findings obtained in the MAAS panel studies will be combined with those obtained for prodromes of dementia and dementia in the Maastricht Memory Clinic (Verhey, 1993) and those in the RNH data base. The present project describes our epidemiological research into the

prevalence of dementia, causes of death, and comorbidity in dementia of patients in the RNH.

Recent cross-national surveys have given increasingly accurate estimates of the prevalence of dementia –especially Alzheimer’s disease– in the general population. Approximately 1.2 million people in the United States (Katzman, 1986) and up to 100,000 in the Netherlands (Hofman & van Duijn, 1992) suffer from severe dementia. Estimates for mild dementia are twice as high, and the numbers are on the increase in view of the anticipated old-age boom. There is uncertainty about the number of people with possible prodromes of dementia, although the prevalence is suggested to be at least four times as high as that of dementia.

Data on the prevalence and incidence of dementia in general practice are sparse. In particular, there is no information on comorbidity and causes of death of demented patients. Several studies have addressed this topic, but studies on well-described patient populations which enable generalization to the general population are needed. This report describes the prevalence and incidence of dementia in the population of the RNH in Limburg, the Netherlands.

MATERIALS AND METHODS

The Registration Network of Family Practices

The Registration Network of Family Practices (Registratienet Huisartspraktijken – RNH) includes the patient data of 42 general practitioners (GP’s) from 15 practices. The general practitioners continuously register demographic data as well as relevant health problems of their patients via a computerized record system (Mersemakers, Höppener, Knottnerus, Kocken, & Limonard, 1992). Health problems recorded include complaints, diagnoses, abnormal findings, risk factors, and some other problems (e.g., adverse drug reactions) that are either permanent, chronic, or recurrent. Data are coded following the ICPC classification (Lamberts & Wood, 1987) and are collected in a large central database. The RNH uses the diagnostic criteria of the International Classification of Health Problems in Primary Care (Classification Committee of WONCA, 1987). On January 1, 1995, the database contained data concerning some 60,000 patients and is still in development. When fully operational, 80,000 patients will be included. Patients from the participating GP’s are entered in the database randomly, and for each patient all data of all previous contacts with the GP are entered at the same moment. Practices are situated in both rural and urban regions in the province of Limburg. Since the subjects in the basic population are included on a random basis, and all Dutch inhabitants are registered at a general practice, the RNH register can be considered as representing the local general population. This procedure permits the use of the database

for (retrospective) cohort or case-control studies. Data from deceased patients are kept separately and can be used for analysis together with the basic data set. Age-specific prevalence and incidence figures for dementia were estimated from data collected within the RNH.

RESULTS

Incidence and prevalence of dementia

The point prevalence for people aged 50 or more was 7.63‰ (95% confidence interval (CI)=6.24–9.02) and the cumulative incidence was 2.04 per 1,000 person years (95% CI=1.76–2.36) (Buntinx, Knottnerus, Jolles, van Boxtel, Muris, Schouten, & Höppener, 1994). The social prevalence was defined as the total number of people with dementia living in the same household as a demented person divided by the total population. This figure was estimated as a measure of the human burden of the disease and was calculated to be 5.31‰ of the total population.

Both the prevalence and incidence increased with age and were higher in women than in men. Dementia tended to occur more frequently in people with a lower education, although this finding was not statistically significant ($p=.08$). A complex interaction existed between age and living pattern, dementia being more frequent in people living with others at older age (age 80 and more) and in people living alone at younger age.

Comorbidity of demented people

The comorbidity of demented people included in the RNH was studied in a cross-sectional study comparing all 115 demented people included in the database with 345 non-demented people matched for age, sex, and education (Kessels & Buntinx, 1995). The number of problems in the problem list was higher in demented people than in the non-demented people ($mean=5.3$ versus 4.0 , respectively; $p<.01$). After exclusion of dementia as a problem, however, these means were very similar and did not differ significantly. The average number of new problems included in 1992 was higher in demented people than in the control population: $.78$ versus $.38$, respectively; $p<.001$. There were no significant differences between both groups when ICPC letter groups were compared. The number of cancers and the number of chronic diseases were almost similar. We compared the prevalence of 70 previously selected problems. In only five cases, there was a significant difference between both groups. This was very similar to the significance level that was used ($p=.05$).

Causes of death of demented people

In a cross-sectional study, the causes of death of 77 deceased patients with dementia were compared to the causes of death of all 658 other deceased patients within the RNH database of deceased patients. At the moment of death, the mean age and number of problems in the problem list were higher in the group of demented people than in the non-demented people: 83 versus 80 years and 6.5 versus 5.9 problems. Cardiovascular diseases were the most frequent cause of death in both groups. In contradiction with some other studies, especially those concerning institutionalized persons, pneumonia was rarely a cause of death.

The relationship between old age, depression, and subsequent dementia. It has been hypothesized that depression in the elderly could be a predictor, and even an etiological agent, of dementia. In a retrospective cohort study, based on the RNH, we tested the hypothesis that elderly patients with a diagnosis of depression would have a higher rate of subsequent dementia, than those not suffering from depression.

The relative risk of a diagnosis of dementia in patients *with* versus *without* previous depression was 1.18 (95% *CI*=.61–2.27) for people aged 70 or older, and 1.01 (95% *CI*=.43–2.38) for those aged 80 or older. In neither of the age groups was there a significant relationship between depression and subsequent dementia.

DISCUSSION

The results described in this paper underscore the notion that a register of general practices can yield data that is relevant to cognitive aging and dementia research. The data obtained in this sample were in some respects different from those obtained in regular population studies. Specifically, differences in the incidence and prevalence data (probably representing different concepts of disease used in population studies and general practice studies), the comorbidity data and some results on the relationship between old age, depression, and subsequent dementia are of particular relevance.

With respect to future research in relation to the MAAS study, emphasis will be placed on research based on the uses of RNH and RCAD databases in combination. As the patients selected for the MAAS panel studies are not a random sample of the RNH database, this cohort cannot be seen as a regular epidemiological study cohort. Patients that returned the MAAS-A₁ postal questionnaire were compared to the initial RNH population and were found to be reasonably similar with respect to age, sex, education, number of problems in the problem list, and diagnoses in the problem list according to the ICPC letter groups (see Section 3.2). Apart from those diagnostic categories that serve as exclusion criteria for

the main study, both populations were also reasonably similar with respect to a selection of specific ICPC codes that were tested.

The RNH database contains ample data about the medical problems of all patients, whereas the MAAS database (RCAD; Section 4.4) contains additional demographic, medical, psychosocial and cognitive data for all patients (eventually up to 3,500) included in the postal survey and in the experimental panel studies A₁ to A₄. As all patients who participated in the MAAS programme were selected from the RNH database, coupling the data from the RNH database and the RCAD database enables the study of several other research questions. A special procedure was designed to guarantee anonymous coupling of data from both databases. The following studies that make use of combined data are in progress or will be started shortly.

- (1) A study comparing the data recorded in the RNH database and obtained with the MAAS postal survey. The aim of this study is to compare the information obtained with health problem oriented medical diagnosis with data on health status obtained in the postal survey. This will enable us to study the strengths and weaknesses of both registration methods.
- (2) A study of experienced health, as described by the patients in the postal survey in relation to the number of problems and the presence of specific problems, as indicated by the problem list of the general practitioner.
- (3) A study of determinants of co-morbidity. The level and characteristics of co-morbidity, as abstracted from the RNH database, will be compared with background data coming from the MAAS postal survey.
- (4) A study of the relationship between work pattern and health. The description of the work pattern, especially irregular working hours, given in the MAAS postal survey will be compared with the health pattern as abstracted from the RNH database.

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